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# The benefits and harms of receiving a polycystic ovary syndrome diagnosis: a qualitative study of women's experiences

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**STUDY QUESTION:** What are the benefits and harms of receiving a polycystic ovary syndrome (PCOS) diagnosis in a community sample of women, including impact on psychosocial wellbeing, lifestyle choices and behaviour?

**SUMMARY ANSWER:** Although some women benefit considerably from the diagnosis, such as through increased awareness and reassurance, women with minimal symptoms may experience more harm than benefit, including long-lasting anxiety and altered life plans.

**WHAT IS KNOWN ALREADY:** Disease labels can validate symptoms and play a vital role in understanding and coping with illness; however, they can also cause harm by evoking illness schemas about severity and permanence. Regarding PCOS, the diagnostic criteria have expanded over time to include women with milder phenotypes (such as those without signs of androgen excess). This has occurred despite limited investigation of the benefits and harms of the diagnosis and has increased the number of women diagnosed.

**STUDY DESIGN, SIZE, DURATION:** Semi-structured interviews were conducted face-to-face or by telephone with 26 participants from April–July 2018 to explore women's experiences with the diagnosis, including the benefits and harms of receiving the diagnosis and the impact on their life.

**PARTICIPANTS/MATERIALS, SETTING, METHODS:** In total, 26 women in the community self-reporting a diagnosis of PCOS (reporting mild to severe symptoms) made by a medical doctor, aged 18–45 years and living in Australia were recruited through social media. Data were analysed thematically using Framework analysis.

**MAIN RESULTS AND THE ROLE OF CHANCE:** The study identified a range of both positive and negative effects of a PCOS diagnosis in the immediate, short and long-term, which were influenced by symptom severity, expectations and experience. For women with previously unexplained and bothersome symptoms, it was a relief to receive a diagnosis, and this resulted in an increased understanding about the importance of a healthy lifestyle. By contrast, women with milder symptoms often reported feeling shocked and overwhelmed by the diagnosis, consequently experiencing anxiety about the associated long-term risks. The majority of women, regardless of symptom severity, experienced prolonged worry and anxiety about infertility, resulting for some in risk taking with contraception, unintended pregnancies, pressure to conceive early or altered life plans. With time, many women developed positive coping strategies and perceived the diagnosis to be valuable, including those who felt they had experienced minimal benefit or even harm.

**LIMITATIONS, REASONS FOR CAUTION:** PCOS diagnosis was self-reported and the sample was highly educated.

**WIDER IMPLICATIONS OF THE FINDINGS:** Fear of infertility was salient for many women, underscoring the need for accurate information, counselling and reassurance of fertility potential. Given the risk of significant consequences, health professionals should use a tailored approach to PCOS diagnosis to increase the benefits of appropriate and timely diagnosis for women affected by significant symptoms, while reducing the harms of unnecessarily labelling healthy women for whom the benefits of a diagnosis are small.

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**Key words:** polycystic ovary syndrome / disease labelling / psychosocial / fertility / contraceptive use/ behaviour / benefits / harms

## WHAT DOES THIS MEAN FOR PATIENTS?

Little is known about the impact of a diagnosis of PCOS on women's psychosocial well-being, behaviour and life choices. This is an important issue because the definition of PCOS has expanded to include women with milder forms of PCOS (such as those without signs of androgen excess), and therefore more women are being diagnosed.

This study explored the benefits and harms of being diagnosed with PCOS for women in the community. We found that some women benefited greatly from a diagnosis of PCOS. For example, the diagnosis gave them an explanation for bothersome symptoms and a greater understanding of how to look after their health. However, for women with very mild PCOS symptoms, the diagnosis often brought long-lasting fear and anxiety with few positive effects.

Most women in the study were worried about being infertile, despite research showing many women with PCOS have the same number of children as women without PCOS. Our study shows how fear of infertility can result in stress and anxiety, pressure to change life plans, risk-taking with contraception and, for some, unplanned pregnancy.

These findings highlight the importance of a more tailored, personalized approach to diagnosis and providing good quality information about fertility.

## Introduction

Polycystic ovary syndrome (PCOS) is the most commonly diagnosed endocrine disorder in women of reproductive age and is associated with infertility and adverse reproductive, metabolic and cardiovascular outcomes, such as insulin resistance, obesity and type II diabetes (Dumesic et al., 2015). Symptoms of PCOS include menstrual irregularities (oligo- or anovulation), signs of androgen excess [e.g. hirsutism (male-pattern hair growth), acne] and polycystic appearing ovaries (The Rotterdam ESHRE/ASRM PCOS Workshop, 2004).

Diagnosis can be challenging as symptoms vary in severity and it can be difficult to differentiate normal variability from the abnormality of PCOS, especially in young women (Skiba et al., 2018). Symptoms can also vary by weight and ethnicity and can change across the lifespan (Dumesic et al., 2015). Given this complexity and uncertainty, it is not surprising that many women report experiencing long delays and seeing multiple providers before receiving a diagnosis (Gibson-Helm et al., 2016), resulting in a negative impact on psychosocial outcomes and quality of life (Kitzinger and Willmott, 2002; Avery and Braunack-Mayer, 2007). To add to the uncertainty, diagnostic criteria for PCOS have expanded over time (Table 1) to include women with milder phenotypes of PCOS (such as those without signs of androgen excess), without clear evidence of benefit (Wang and Mol, 2017), increasing the number of women diagnosed (Copp et al., 2017a; Skiba et al., 2018). As a result, there is concern over both underdiagnosis and overdiagnosis of PCOS (Copp et al., 2017a; Gibson-Helm et al., 2016; Skiba et al., 2018).

Potential benefits of receiving a PCOS diagnosis include an explanation and validation of symptoms (Avery and Braunack-Mayer, 2007; Rowlands et al., 2016). It is also suggested that a timely diagnosis may help women with family planning, improve access to treatment and motivate them to implement healthy lifestyle changes to reduce the metabolic and cardiovascular risks associated with PCOS (Chan et al.,

2017; Cooney and Dokras, 2018). However, it is unclear whether knowledge of the diagnosis reduces these risks. Additionally, the additional phenotypes introduced by the expanded Rotterdam criteria do not have the same increased risk of long-term implications (Daan et al., 2014; Lizneva et al., 2016b; de Wilde et al., 2017), and current evidence is limited by referral bias as most studies recruit women from specialist clinics, hospital settings and PCOS support groups, who typically have more severe symptoms than women in the community (Azziz et al., 2016; Lizneva et al., 2016a).

This uncertain benefit of a diagnosis needs to be weighed against the potential harms of disease labelling. An increasing body of research in various medical conditions suggests that there are psychological, social, physiological and behavioural harms associated with labelling people with a medical diagnosis (Ogedegbe, 2010; Nickel et al., 2017; Hanmer et al., 2019; Turnwald, 2019). One reason for concern over unnecessary labelling of PCOS is that women with PCOS have higher levels of depressive symptoms, anxiety symptoms, disordered eating behaviours and poorer self-esteem (Dokras et al., 2011; Dokras et al., 2012; Rowlands et al., 2016; Damone et al., 2018; Lee et al., 2018). It is unclear whether these problems are a direct consequence of the condition itself and its symptoms or whether they may also be due to the PCOS label and its associated long-term implications (Moran et al., 2012; Veltman-Verhulst et al., 2012; Cooney et al., 2017; Copp et al., 2017b; Damone et al., 2018). Several studies suggest potential psychological harms associated with a diagnosis of PCOS. Diagnosed women may perceive they have poorer control over their weight (Lin et al., 2018), despite no clear evidence of such links (Kataoka et al., 2017; Brower et al., 2018). They may also fear infertility, despite similar live birth rates to women without PCOS (Holton et al., 2018; Varanasi et al., 2018). Qualitative findings of small clinical samples or women recruited from PCOS support groups suggest that, in addition to psychological distress (Jones et al., 2011), the prospect of infertility may also have behavioural consequences, such as unprotected sex due

**Table 1 Existing diagnostic criteria for PCOS.**

National Institutes of Health (1990) (Zawadzki, 1992)	Rotterdam* (2003) (The Rotterdam ESHRE/ASRM PCOS Workshop, 2004)	Androgen Excess and PCOS society (2006) (Azziz et al., 2006)
Need both: <ul style="list-style-type: none"><li>- Oligo-ovulation or anovulation</li><li>- Clinical or biochemical signs of hyperandrogenism</li></ul> And exclusion of other causes	Need two of the following: <ul style="list-style-type: none"><li>- Oligo-ovulation or anovulation</li><li>- Clinical or biochemical signs of hyperandrogenism</li><li>- Polycystic ovaries on ultrasound</li></ul> And exclusion of other causes	Need: <ul style="list-style-type: none"><li>- Clinical or biochemical signs of hyperandrogenism</li></ul> AND one of the following: <ul style="list-style-type: none"><li>- Oligo-ovulation or anovulation</li><li>- Polycystic ovaries on ultrasound</li></ul> And exclusion of other causes

\*Endorsed in 2018 by new international guidelines on PCOS for use in adult women (Teede et al., 2018). PCOS: polycystic ovary syndrome

to perceptions of infertility (Jones et al., 2011) or feeling pressured to have children earlier than planned (Williams et al., 2015). Whether women in the community and those with milder symptoms have similar experiences is unclear.

Overall, evidence of the impact of a diagnosis of PCOS is scarce, and no studies have explicitly investigated the benefits and harms of receiving a diagnosis from the women’s perspective. Given the risk of both underdiagnosis and overdiagnosis, the uncertain clinical benefit of knowing this diagnosis needs to be weighed against the potential harms in women labelled with PCOS. We addressed these knowledge gaps by qualitatively exploring the balance of benefits and harms of receiving a PCOS diagnosis for women in the community who vary in type and severity of symptoms. In particular, we explored from women’s perspectives the impact of the diagnosis on their psychological well-being, lifestyle and behaviour, over the short and long term.

Materials and Methods

Design

This qualitative study used semi-structured face-to-face and telephone interviews to explore women’s experiences with the diagnosis and management of PCOS, including the benefits and harms of receiving the diagnosis and the impact on their life (see Supplementary Data A for the Consolidated Criteria for Reporting Qualitative Studies checklist).

Ethics approval

Approval was obtained through the University of Sydney Human Research Ethics Committee (number 2017/878). Each participant provided written informed consent.

Sample

Participants were 26 women self-reporting a diagnosis of PCOS. Inclusion criteria included a diagnosis of PCOS by a medical doctor, currently aged 18–45 years and living in Australia.

Recruitment

Participants were recruited through paid Facebook advertising. Social media was utilized in order to recruit a more diverse sample than previous studies, which tended to recruit women from outpatient clinics or PCOS online support groups only, where women typically

have more severe symptoms and phenotypes (Azziz et al., 2016). The advertisement directed interested respondents to the participant information statement and a questionnaire (Supplementary Data B) used to collect contact details and self-reported symptoms and severity of PCOS. This information was used to purposively identify participants with a range of different PCOS symptoms and severity levels (maximum variation sampling; Palinkas et al., 2015).

Given that women with milder symptoms and signs of PCOS have been under-represented in previous literature, a second advertisement specifically targeted to women who identified with mild PCOS was later used to ensure that such women were well represented in the sample. A total of 71 women expressed interest in being involved in the study and completed the questionnaire. Thirty-seven responded to the first advertisement (of which 19 were contacted and 18 were interviewed) and 34 responded to the second advertisement (of which eight were contacted and were interviewed). Recruitment continued until preliminary analysis during data collection suggested thematic consistency regarding the benefits and harms of receiving a PCOS diagnosis, indicating saturation of key themes.

Data collection

The semi-structured interview guide was developed by the whole research team, based on themes identified in previous literature and gaps in the evidence, and reviewed by the PCOS consumer panel. The guide was first piloted with three women with PCOS. Topics included participants’ experience with diagnosis and management, perceived benefits and harms of receiving the diagnosis and the impact of the diagnosis on their life (Supplementary Data C). The interviewer was a female public health researcher with a background in psychology and experience with conducting qualitative interviews. Interviews were conducted between April and July 2018, lasted 25–80 min and were audio-recorded and transcribed verbatim.

Analysis

Interview data were analysed thematically using Framework analysis (Ritchie, 2003). To ensure rigour, a step-by-step collaborative approach to analysis was undertaken. Throughout data collection, the interviewer (T.C.) regularly met with colleagues (J.J., J.H., K.M., J.D.) to discuss salient impressions as they arose, forming a preliminary list of codes. T.C. then reviewed all transcripts and developed a list of arising salient themes. Three more researchers (K.M., D.M. and J.J.) read a sample of the transcripts to identify additional themes and assist



**Table II** Demographics and self-reported PCOS characteristics in a sample of women from the community (N = 26).

Characteristic	Number (%) of women
<b>Current age (years)</b>	
18–25	9 (35)
26–30	6 (23)
31–35	6 (23)
36–40	2 (8)
41–45	3 (12)
<b>Age at diagnosis (years)</b>	
12–15	3 (12)
16–20	8 (31)
21–25	12 (46)
26–30	3 (12)
<b>Years since diagnosis</b>	
< 1 year	2 (8)
1–3 years	6 (23)
4–9 years	9 (35)
10–15 years	4 (15)
16+ years	5 (19)
<b>Education (highest qualification completed)</b>	
School Certificate (Year 10)	1 (4)
Higher School Certificate (Year 12)	3 (12)
Diploma/Trade certificate	6 (23)
Bachelor degree or above	16 (62)
<b>Relationship status</b>	
Single	8 (31)
In a relationship	7 (27)
Married	11 (42)
<b>Number of children</b>	
No children	17 (65)
1 child	4 (15)
2 or more	5 (19)
<b>Symptoms and signs reported when diagnosed*</b>	
Irregular menstrual cycles	24 (92)
Polycystic ovaries on ultrasound	23 (88)
Acne (pimples)	17 (65)
Hirsutism (excess hair)	15 (58)
Weight gain	12 (46)
Alopecia (male pattern hair loss)	2 (8)
Difficulty falling pregnant	5 (19)
<b>Number of symptoms and signs reported*</b>	
1 symptom	1 (4)
2 symptoms	5 (19)
3 symptoms	4 (15)
4 symptoms	9 (35)
5 symptoms	5 (19)

(Continued)

**Table II** Continued

Characteristic	Number (%) of women
6 or more symptoms	2 (8)
<b>Possible phenotype of PCOS**</b>	
Oligo/anovulation, signs of hyperandrogenism + polycystic ovaries	13 (52)
Oligo/anovulation + signs of hyperandrogenism	3 (12)
Signs of hyperandrogenism + polycystic ovaries	1 (4)
Oligo/anovulation + polycystic ovaries	8 (32)
<b>Self-reported severity of PCOS*</b>	
Unnoticeable	3 (12)
Mild	12 (46)
Moderate	8 (31)
Severe	3 (12)
<b>Self-reported impact of PCOS on life*</b>	
No impact at all	1 (4)
Minimal	7 (27)
Moderate	10 (38)
Significant	6 (23)
Extremely significant	2 (8)

\*Data from responses to recruitment questionnaire (see Supplementary Data B)

\*\*phenotype is based on self-reported symptoms, so should be interpreted as a rough guide only (n = 25 as one participant reported polycystic ovaries only but recalled her doctor specifically diagnosing PCOS)

in drafting the coding framework, which was also informed by the interview guide. The data set was then coded by T.C. A random subset of the data (10%) was double coded by D.M. to ensure consistency. Similarities or differences in the coding were discussed and re-assessed. Prominent themes were then identified and discussed in-depth with the research team to develop the interpretation of overall study findings.

## Results

### Sample characteristics

The mean age of participants was 29.3 years, over half had a bachelor degree or higher, and most were in a relationship or married (Table II). The majority had been diagnosed between the ages of 16 and 25 years. The symptom that most often prompted seeking medical attention was irregular cycles. Time since diagnosis varied from 6 months to 27 years (median 6.5 years) and time from first seeking medical attention to receiving diagnosis ranged from 1 week to 8 years. Participants varied widely in symptoms reported, number of symptoms at diagnosis, self-reported severity of PCOS and impact on life.

### Thematic analysis findings

Four main themes were identified relating to the impact of being diagnosed with PCOS: initial appraisal, psychological impact, behavioural consequences and coming to terms with the diagnosis. Participant quotes are used to illustrate themes. Additionally, three case studies highlight individual stories of women who represent diverse experi-

ences across these four themes and differ regarding their expectations, symptoms and experience. Pseudonyms are used throughout.

## Initial appraisal

Initial appraisal and personal interpretations of the PCOS label varied widely and were influenced by a number of factors, such as symptom severity, pathway to diagnosis, expectations and the doctor's approach to communication. Some women had long suspected they might have PCOS and were relieved to finally have an explanation for previously ongoing, bothersome symptoms.

*'In a way relieved because I finally knew that there was something, it wasn't just my imagination. It wasn't just me saying, you know, there's something not right and nothing was found.'* (Maree, 32 years, age diagnosed: 30 years).

Others expressed feeling shocked by the diagnosis, or feeling alarmed and overwhelmed, as they had perceived their symptoms to be relatively minor and had not considered them indicating a serious condition. These feelings were further exacerbated after hearing about the associated risks of PCOS, such as infertility, endometrial cancer and type II diabetes.

*'This is just like really out of the blue. 'Cause I remember like my intention coming to the GP was, oh, my period's just a little bit irregular, can you put me on a pill to be regular? ...And in my head it's like, oh, it can't be that serious, right? I just want my period to be regular.'* (Gloria, 25 years, age diagnosed: 19 years).

A few women had mixed emotions, where the diagnosis initially brought relief to have an answer for bothersome symptoms, but also uncertainty and stress regarding their future.

*'Maybe a little bit relieved to know what was wrong with me and that it could sort of be managed. But probably more sort of worried about how it was going to affect me in the future.'* (Ella, 27 years, age diagnosed: 16 years).

Many expressed frustration, sadness and despair regarding the lack of long-term solutions, contributing to feelings of dissatisfaction with the diagnostic experience.

*'But it was also a bit upsetting to know, well we really don't know a lot about it, we don't know how to cure it.'* (Louise, 43 years, age diagnosed: 15 years).

On the other hand, a couple of participants described feeling 'indifferent', not bothered about their diagnosis or that it 'didn't really matter' (Darcy, 20 years, age diagnosed: 20 years). These participants were often diagnosed in their late teens or early 20's and stated that they were not 'ready to hear it' (Christina, 37 years, age diagnosed: 20 years) or willing to engage with it, as the long-term implications seemed too far away to consider.

*'She thought I'd be really concerned about that but really kids is the last thing on my mind. I'm just trying to finish my degree (laughs).'* (Darcy, 20 years, age diagnosed: 20 years).

## Psychological impact of being diagnosed with PCOS

Women described various positive and negative impacts on their psychological well-being as a result of being diagnosed with PCOS, which were influenced by the symptoms they experienced and their expectations at diagnosis.

### Positive impact

For some women experiencing bothersome symptoms, the diagnosis validated their symptoms and had a positive impact on their psychological well-being. Prior to being diagnosed, these women described feeling abnormal and that they were 'turning into a boy' (Louise, 43 years, age diagnosed: 15 years). Receiving a medical diagnosis legitimized their experience and made them feel less abnormal.

*'It wasn't just me, it was actually a hormonal illness.'* (Kate, 18 years, age diagnosed: 12 years).

Some felt reassured to find out (either from their doctor or via searching online) that PCOS is common, and benefited from knowing they were not 'the only person that experiences this' (Elisabeth, 31 years, age diagnosed: 20 years).

Many participants commented that the diagnosis brought increased understanding and clarity about how their body works (Case study 1). Two women said this resulted in them feeling empowered and in control regarding management, and that the diagnosis opened doors to accessing treatment.

*'I guess mentally and emotionally I feel that it was benefit to have that diagnosis to be explained, you know, that myriad of factors that was sort of going on with my health. Um, it also allowed me access to, you know, medication like Metformin, which is typically used for diabetes management.'* (Anna, 24 years, age diagnosed: 19 years).

## Case study 1. ANNA

Anna was diagnosed at 19 years old (life stage: late adolescence) and was 24 years when interviewed. Anna reported having symptoms since puberty, such as seemingly inexplicable weight gain, irregular menstruation and excess hair growth (symptoms: bothersome). She visited the doctor about her symptoms when she was 15 years old and was prescribed the oral contraceptive pill but was not officially diagnosed until, aged 19 years, she raised the possibility of PCOS to her GP herself (expectations: suspects PCOS). Anna felt 'frustrated' that the GP dismissed her symptoms as 'just a regular part of puberty' and attributable to her failure in maintaining a healthy lifestyle.

**Initial reaction:** For Anna, receiving the diagnosis was a 'relief' as it was something that she had suspected for some time and it 'provided an answer' to symptoms, such as her weight management, which she felt she was being 'unfairly blamed for'.

**Psychological impact:** The diagnosis had a positive impact on Anna's well-being, as prior to being diagnosed she felt that she was being blamed for her symptoms, which had started to impact her emotionally and psychologically. The diagnosis gave her increased understanding and reassurance, which stopped her from feeling at fault for her symptoms.

**Table III** Fertility-related psychosocial impacts of the PCOS diagnosis.

Psychosocial impact	Supporting quote
Emotional impact and thought processes	'I feel really crappy just about being diagnosed and about being diagnosed while wanting to start [trying] for a baby' (Harriet, 29 years, age dx:29, 0 children)
Perceived loss of control	'The implications for fertility ... because it's not something that anyone wants to have decided for them. That if you're going to have kids or not have kids, then it feels like it should be something you choose. Like to have that, um, imposed is quite disempowering.' (Alex, 35 years, age dx:25, 0 children)
Threatened expectations and dreams for the future	'It's challenged my whole idea of what I wanted for my future. It's like that idea has been shaken a bit ... I really just don't know what's going to happen. What will happen if I can't have a baby at all? And the thought just absolutely petrifies me.' (Harriet, 29 years, age dx:29, 0 children)
Altered parenthood goals	'I think that I have accepted that it's likely ... to be difficult for me to have kids. And, um, and so ... it's not something that I've ever really pursued.' (Alex, 35 years, age dx:25, 0 children)
Persisting fear of infertility despite previously conceiving naturally without difficulty	'I remember second time round, 'cause I was a bit older, and I was planning to have a second baby and, um ... I remember it didn't happen for 6 months so I got myself quite upset by that, and thought that's it, this is the infertility ... I felt like I was in a rush a little bit. I panicked. Because I sort of felt I was on the back foot with PCOS.' (Annette, 43 years, age dx:22, 2 children)

Fear of infertility: Learning of the risk of infertility had a negative impact, however, as she had always *'counted on being able to have children'*. Anna described how the diagnosis gave her *'some concerns and worries'* about her fertility, which were difficult to process at her age.

Behavioural consequences: Anna described how her perceptions of her reduced fertility resulted in her taking risks with contraception as she *'became convinced'* that children would not be an option and ended up falling pregnant aged 19 years. Deciding whether to continue with the unintended pregnancy was an extremely emotional process. Anna was concerned that she might never get pregnant again and did not feel she would be able to live with herself if she *'terminated a pregnancy and then struggled in 10 years'* when she felt ready to have a child. She described feeling *'very angry'* that no one had told her that the effect of PCOS on her fertility was not as severe as it was made out to be. Anna's understanding of her fertility from that diagnosis resulted in her decision to continue with her pregnancy, *'which was unexpected, and become a single parent at aged 20.'*

Coming to terms with the diagnosis: Anna described how PCOS is now just something that she lives with and that she does not think about it often, aside from when she would consider having more children. Overall, Anna feels that being diagnosed with PCOS was *'a very positive experience'* as having the diagnosis and explanation *'resolved a lot of questions'* about her health. (\*Italicized text indicates verbatim quotes).

**Negative impact**

Some women reported feeling embarrassed by having PCOS, as for them the diagnosis *'sort of makes you feel like there's something ... something bad wrong with you, that you have too much testosterone.'* (Ella, 27 years, age diagnosed: 16 years). Two women described how the diagnosis threatened their self-image, as it did not fit with their perception of being healthy.

*'I always consider myself very healthy and then I'm like, oh no, I do have that thing (laughs).'* (Julia, 28 years, age diagnosed: 19 years).

There were also consistent reports of diagnosis-related fear and worry about the future. Upon receiving the diagnosis, many women experienced

persistent fears of becoming overweight or developing type II diabetes. This included women for whom PCOS was the only risk factor for diabetes and who were likely to be at lower risk of metabolic consequences (such as those of normal weight without insulin resistance).

*'I'm a little bit nervous in terms of, um, well mostly concerned because it increases the risks of a lot of chronic diseases.'* (Julia, 28 years, age diagnosed: 19 years).

**Fear of infertility**

For most women, there was a strong focus on fertility and the inherent uncertainty the diagnosis brings. Women reported feeling *'super sad'* (Harriet, 29 years, age diagnosed: 29 years) when contemplating their ability to conceive and described fear of infertility being *'always in the background'* (Ella, 27 years, age diagnosed: 16 years). This was the case even if they had previously conceived without difficulty. Some participants discussed how the diagnosis and their pervasive worry about future infertility influenced when they would start trying for a baby. Ella, for example, described PCOS as *'dictating'* her decision to begin trying to conceive *'earlier rather than later'*. Some described how their potentially reduced ability to conceive threatened their expectations and dreams for the future, causing stress and anxiety. Others reported beginning to question what they wanted for the future, considering their life without children or changing their plans to have children. Table III provides examples of these fertility-related impacts of the PCOS diagnosis.

**Behavioural consequences**

Women's reports highlighted several motivational, social and behavioural consequences stemming from the PCOS diagnosis, with the majority related to the associated risk of infertility.

**Risk taking with contraception**

Many discussed how the diagnosis and their perceptions of reduced fertility resulted in taking risks with contraception. Three women also reported unintended pregnancies due to the belief that they would

need medical assistance to conceive and that contraception was likely not necessary.

*'I basically thought that I would never get pregnant, so the unplanned pregnancy happened . . . you really do get that argument in your head that, look it's not easy for me, I may never get pregnant, so you know, you're not always that careful.'* (Louise, 43 years, age diagnosed: 15 years).

### Family planning

Some women discussed feeling pressured to have children earlier than they would have liked because they were concerned that if they left it later they would be unable to conceive. A few women did have children earlier than preferred, which was seen to impact on their careers.

*'Yes, that did put the career on hold. I focused on having the children early... I felt with the diagnosis, yeah, you're always thinking about, you know, that fertility side of it. So, yeah, it does affect your decisions.'* (Louise, 43 years, age diagnosed: 15 years).

Some women also discussed how they would not terminate an unintended pregnancy if it was to occur due to worry that it might be their only chance to conceive (Case study 2).

*'Even if we aren't ready we don't really want an abortion because it could be our only chance to create a life between us.'* (Gloria, 25 years, age diagnosed: 18 years).

Conversely, a few women were diagnosed with PCOS after experiencing infertility and felt frustration and anger that the condition had not been picked up sooner. These women often wished they had known about the risk of infertility so they could have started trying to conceive earlier.

*'My biggest gripe was the fact that I have had irregular periods my whole life . . . it was only really when I was trying to get pregnant that it was picked up . . . my husband and I probably would have started trying to conceive much earlier.'* (Madeline, 37 years, age diagnosed: 29 years).

There were, however, a minority of participants who reported that the diagnosis had no impact on family planning.

*'We are trying for a second at the moment. But that's more looking at my age more so than anything specific with the PCOS.'* (Alison, 34 years, age diagnosed: 22 years).

## Case study 2. GLORIA

Gloria was diagnosed at 18 years old (life stage: late adolescence) and was 25 years when interviewed. Gloria was diagnosed after having irregular periods since puberty. She was referred to a gynaecologist, and test results showed polycystic ovaries and abnormally high androgens. Gloria described having acne, but as she has had no trouble with excess hair or weight, considers her PCOS as mild (symptoms: mild). The gynaecologist explained to Gloria that PCOS will decrease her fertility rate and increase her risk of diabetes.

Initial reaction: Gloria described feeling *'a bit scared'* when diagnosed and described how it was a *'serious medical condition'* and it felt *'really out of the blue'* (expectations: PCOS unexpected). The diagnosis for Gloria was *'quite confronting'*, as it is something that *'can affect your lifestyle and quality of life'*. However, Gloria reflects that *'it could have been a lot worse. It could have been cancer or anything. But really it's just an irregularity of your hormones, unfortunately.'*

Psychological impact: Although being diagnosed has not changed her way of life, Gloria reports that having the diagnosis has *'cleared up a lot of cloud'* in her mind and increased her understanding.

Fear of infertility: The information about her reduced fertility was *'pretty confronting'* for Gloria as she did not think it would have any effect on her fertility, and it has made her *'very apprehensive'*, causing her to question whether she wants children, when to start trying for children, and whether she should even try if her chances are already decreased.

Behavioural consequences: Gloria discussed how she has had conversations with her partner about how PCOS can affect fertility and how if they fell pregnant unintentionally they would continue with the pregnancy even if they were not ready for a baby, due to risk of future infertility.

Coming to terms with the diagnosis: Gloria reports that her only worry is the uncertainty surrounding her fertility. However, she further goes on to explain that she tries to *'see it as a positive'* as now she has the diagnosis she knows what to do. Overall, Gloria finds her PCOS *'manageable'* and often forgets she has PCOS as *'it's really nothing'* and it *'doesn't play a huge part'* in her life at the moment.

### Interactions with partners

Participants reported both positive and negative impacts of the diagnosis on their relationships with their partners. A few women discussed how the diagnosis placed pressure on the couple to start a family earlier than they would have liked, and some reported feeling obligated to discuss their diagnosis early in the relationship to make the partner aware of their potentially reduced fertility.

*'Obviously I had to tell him about the fact that I knew I could not conceive naturally. So that was very difficult for me. I was very nervous 'cause it's a very hard thing to, to say to someone when you're in a new relationship and you don't want to freak anyone out either when it's new, but I just felt that when you're with someone that they deserve to know if you feel that it's going to be serious.'* (Ciara, 26 years, age diagnosed: 21 years).

Others reported the diagnosis strengthened their relationship through newfound support from their partner or gaining greater clarity as to why they were struggling to conceive.

*'He now understands a bit better what I'm going through . . . now that he knows it's actually real, it's actually a condition he's a bit more supportive . . . it's actually been quite positive.'* (Maree, 32 years, age diagnosed: 30 years).

### Diet and exercise changes—the good and the bad

Regarding lifestyle recommendations, some women reported the diagnosis was *'a wake-up call'* (Annette, 43 years, age diagnosed: 22 years) through increased awareness about the higher risk of developing



type II diabetes, and it motivated them to implement healthy lifestyle changes.

*'I'm one step ahead of knowing I might be susceptible to getting diabetes... I lost weight, which was probably a healthy thing to do.'* (Annette, 43 years, age diagnosed: 22 years).

However, many participants at the same time spoke of their struggle to maintain their motivation and weight over time, illustrating the challenge with maintaining lifestyle changes. Others discussed difficulty in finding motivation or felt no need to alter their lifestyle. A few participants also described becoming 'obsessed about' (Louise, 43 years, age diagnosed: 15 years) maintaining a healthy lifestyle due to fear of weight gain and developing associated problems like diabetes, which affected their psychological well-being.

*'I was probably worried that I was going to become overweight and maybe a little bit paranoid about making sure I didn't eat too much and making sure I exercised.'* (Ella, 27 years, age diagnosed: 16 years).

## Coming to terms with the diagnosis

Although participants varied in their experiences and consequences of receiving a diagnosis of PCOS, the majority developed positive coping strategies, such as thinking optimistically and coming to terms with the diagnosis, either through resignation or acceptance. Some participants also expressed forms of resilience and strengthened resolve around their health and described their personal strength to carry on and put things into perspective.

*'I guess just knowing that at the end of the day I have it. There's nothing I can do about being diagnosed with it. It is what it is. It's part of who I am now and just trying to take that in my stride and deal with it in my everyday life, it's up to me how my thoughts are affected by it really.'* (Harriet, 29 years, age diagnosed: 29 years).

Participants discussed the wide variation in PCOS symptom severity, often comparing their symptoms to other women with PCOS (either friends or others encountered online) and saying they felt fortunate their PCOS was quite mild in comparison, illustrating their positive outlook towards their own situation.

*'Compared to some women who have, you know, really unfortunate symptoms, I'm pretty lucky . . . it could be much worse so I don't really mind it.'* (Amy, 31 years, age diagnosed: 15 years).

## Weighing up the benefits and harms of a diagnosis

When asked to weigh up the benefits and harms, most participants perceived the diagnosis to be more beneficial than harmful and were glad to know they had PCOS, even those who had been negatively impacted or considered the diagnosis to provide minimal benefit.

*'I don't know. I think the immediate . . . the immediate benefit to harm was definitely harmful. Um, more of the emotional and psychological stuff . . . But I think in the long-term having that*

*diagnosis helps in the physical regard to manage the symptoms and . . . maybe not just even manage the symptoms but manage the condition and just to be aware of it.'* (Alex, 35 years, age diagnosed: 25 years).

A few women described an equal balance of benefits and harms, and two women reported more harm than benefit (Case study 3).

*'I would say 50/50 definitely. Because I've been diagnosed, you know, you're aware, you can learn how your body is working, you can learn what is good and bad for your body and how to manage it . . . but again, harm I would say 50% because of the mental health side of things. It can be really, you know, stressful [in regards to fertility etc].'* (Nicole, 31 years, age diagnosed: 24 years).

## Case study 3. JULIA

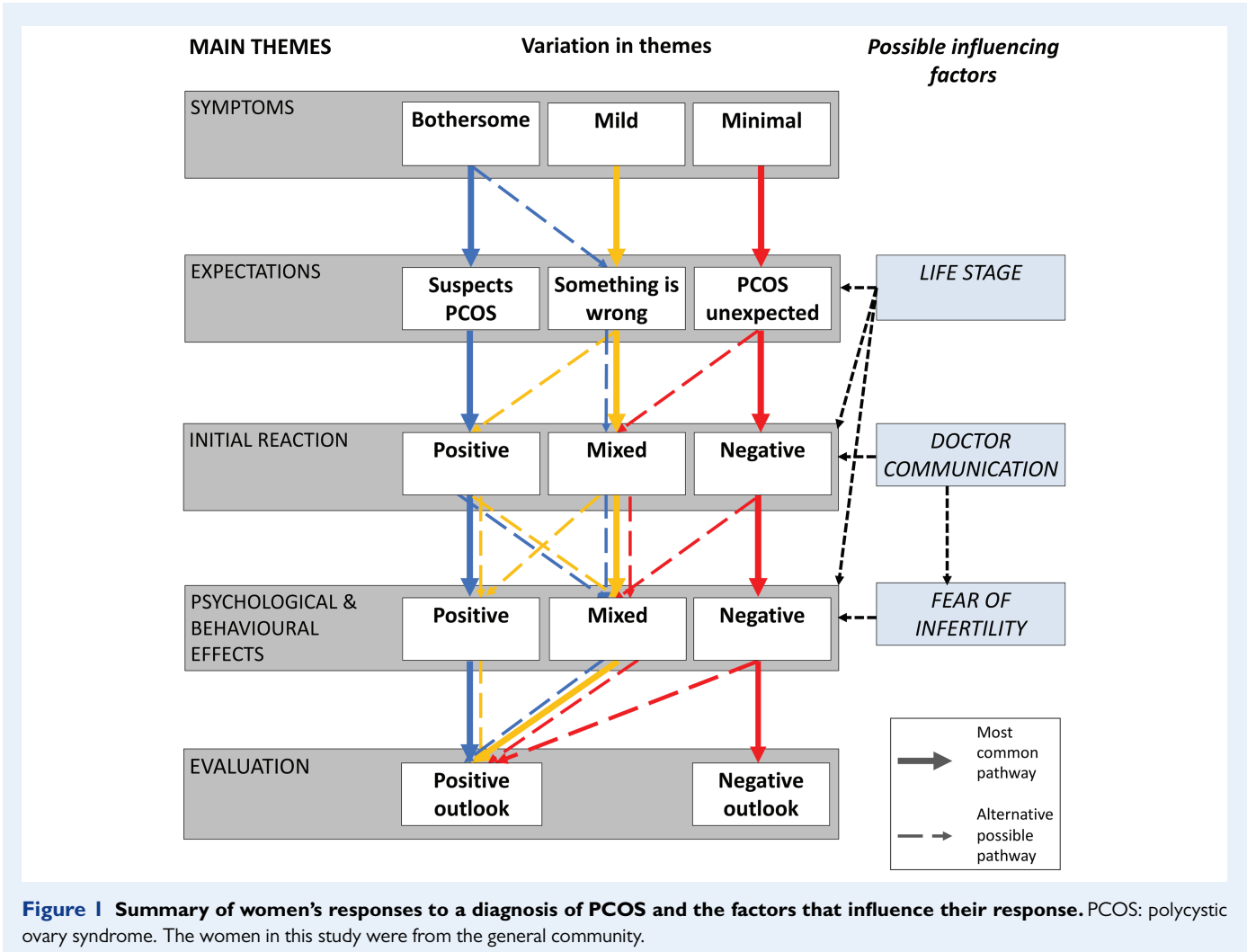
Julia was diagnosed at 19 years old (life stage: late adolescence), and was 28 years when interviewed. She was diagnosed as a result of an MRI for a hip injury, which incidentally detected polycystic ovaries. She was referred to a gynaecologist who diagnosed her with PCOS. Prior to diagnosis, Julia acknowledged that she had always had irregular periods, but did not seek medical advice as she thought it was 'probably normal' as she was 'very active' and had not really thought about it (symptoms: minimal).

**Initial reaction:** The PCOS diagnosis was very unexpected and the risks of infertility, cancer and diabetes listed by the gynaecologist was 'a lot to take in' so young and 'not the most tactful of deliveries'. Julia described feeling shocked and overwhelmed when diagnosed, as she went in 'with a hip injury and came out with a condition' that she cannot cure (expectations: PCOS unexpected).

**Psychological impact:** The diagnosis for Julia has had a long-lasting emotional impact as worry about fertility and the 'increased risks of a lot of chronic diseases' constantly plays on her mind and makes her feel 'nervous'. Julia often wonders whether it would have been 'better not to have known about it' because she cannot do anything about it except her general lifestyle factors that she does anyway.

**Fear of infertility:** Julia describes how as she gets older she worries more and more about whether she will struggle to conceive and 'whether children will be in the future'. This has had a negative impact on her psychological well-being as it has caused some negative moments in terms of thinking about whether or not she can have children. This has also resulted in some challenging conversations with her partner, which Julia reports has been 'the hardest part to cope with'.

**Behavioural consequences:** The diagnosis has resulted in Julia thinking about trying to conceive 'a lot earlier' than she would have without the diagnosis. Regarding her relationship with her partner, the diagnosis has caused Julia to have conversations with her partner 'early' in their relationship to make sure he knew about the risk of infertility before they 'go any further'. Julia tries to see this as 'a good thing' as when they have difficulty conceiving in the future 'he'll know that already rather than being a little bit more blindsided'. Julia reported making no changes to her health behaviour after being diagnosed as she was 'really active anyway' and that it 'didn't motivate' her to be any more active.



Coming to terms with the diagnosis: Julia expressed both positive and negative attitudes towards her PCOS. She called her PCOS ‘a mild case’ when compared to other people, as she has never had any problems with weight or acne, expressing that she felt lucky she does not have many symptoms. However, Julia also described how she finds the diagnosis ‘really annoying’ as it threatens her perception of being healthy and she perceives no benefit from knowing she has PCOS because it is not something she treats ‘in any particular way’ and often forgets to write on her medical history.

Overall, Julia sees the diagnosis ‘as being more detrimental than being beneficial’ and does not see ‘any benefit to having the diagnosis’ as she does not have many symptoms, it resulted in no changes to management, and it ‘plays on your mind’ due to ‘the associated risks and concerns it brings up in terms of children, and risks of future diseases and other chronic issues.’

Factors influencing the variation across themes

Women’s responses to a diagnosis and the variation across these themes were influenced by a number of factors, including their symptom severity, expectations prior to receiving a diagnosis and diagnostic pathway, life stage, individual differences and the doctor’s commu-

nication at diagnosis, including their description of associated long-term implications such as infertility. The arrows in Figure 1 show these relationships between the main themes..

Discussion

In a community sample of women diagnosed with PCOS, the interpretation of the diagnosis and impact on their lives varied widely and was influenced by factors such as symptom severity, expectations and diagnostic experience. For women with bothersome symptoms, receiving the diagnosis confirmed that their symptoms were genuine, bringing clarity and certainty. The diagnosis provided these women a label with which to explain their experience, positively impacting their psychological well-being. For women with minimal symptoms or for whom the diagnosis was unexpected, their psychological well-being was negatively impacted, and the diagnosis mainly brought uncertainty and worry about the future. A key theme across women was fear of infertility, significantly affecting their lives and relationships. Regardless of their diagnostic pathway or symptom severity, the majority of women came to terms with the diagnosis and ultimately perceived it to be more beneficial than harmful, even those who felt it had brought minimal benefit or even substantial harm. Despite the range in time



since diagnosis, no clear differences in women's experiences were observed.

This is the first study to explore the benefits and harms of receiving a diagnosis of PCOS for women in the community across the spectrum of symptom severity. The use of Facebook advertising allowed recruitment of a community sample of women Australia-wide, contrasting with previous studies that recruited from specialist clinics or PCOS support groups. The interview schedule was developed by a multi-disciplinary team, including experienced qualitative researchers, PCOS experts and consumer representatives (women with PCOS), ensuring suitability and relevance. In addition, rigorous qualitative methods were used in analysis to reach final themes. Study limitations include self-reported diagnosis of PCOS, although reported symptoms were consistent with the Rotterdam criteria (except one participant who despite reporting polycystic ovaries alone identified with the diagnosis of PCOS) and that the sample was highly educated (61% holding a university degree). Although the majority perceived the diagnosis to be mainly beneficial overall, these women have already incorporated PCOS into their identity. As a result, they are subject to biases such as cognitive dissonance, where accepting the diagnosis facilitates the maintenance of positive emotional well-being (Weiss and Bulmer, 2011; Hofmann, 2015).

Our findings bring together two bodies of literature regarding benefits and harms of disease labelling. The benefits described are consistent with previous research about the positive role of diagnostic labels in validating symptoms and supporting patients in understanding, responding to and coping with illness (Avery and Braunack-Mayer, 2007; Noble et al., 2019). At the same time, our findings also attest to negative impacts of disease labelling in inducing unwarranted fear and anxiety, activating schemas about severity and permanence, evoking feelings of hopelessness and resulting in disengagement with treatment and behaviours that are inconsistent with personal goals (Haynes, 1978; Scherer et al., 2013; Shaffer, 2018). More longitudinal research is needed to assess the benefit of knowing this diagnosis on clinical outcomes.

Additionally, women demonstrated several common misconceptions about PCOS, including the belief that PCOS causes weight gain or prevents weight loss (Lin et al., 2018), despite no evidence to suggest this is the case (Kataoka et al., 2017; Brower et al., 2018), and that they were likely infertile, despite similar live birth rates to women without PCOS (Joham et al., 2014; Holton et al., 2018; Varanasi et al., 2018). It was difficult, however, to disentangle whether these misconceptions stemmed mainly from their doctor's communication of associated risks or more from the abundant misinformation about PCOS encountered online (Chiu et al., 2018) or any pre-existing beliefs. These findings emphasize the importance of better evidence-based communication to women and the need to address pre-existing beliefs. Accurate information about the likelihood of pregnancy may provide reassurance and support more informed decision-making about contraception.

In conclusion, our findings highlight the importance of considering the benefits and harms for each individual woman to ensure clear benefit before ascribing the label. Harmful consequences of the diagnosis were evident across the spectrum of symptom severity; however, the perception of benefit was higher for certain groups, such as those with bothersome, impactful symptoms or women struggling to conceive. For these groups, the label seemed to offer notable advantages and our findings highlight the importance of a timely, accurate diagnosis

for these women. For other women, however, a label may not be needed as the benefits of diagnosis were less clear and the risk of harm was high (Moynihan et al., 2019). Instead symptoms could be managed and a healthy lifestyle encouraged without a PCOS diagnosis (Copp et al., 2017a). At the minimum, accurate information and personalized counselling regarding long-term risks in women with milder phenotypes and minimal symptoms is needed to help alleviate anxiety and fear in this expanding patient group.

## Supplementary data

Supplementary data are available at *Human Reproduction Open* online.

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## Authors' roles

T.C., J.J. and K.M. conceived the study. T.C., J.J., K.M., J.H., J.D., A.D. and B.W.M. were involved in designing the study and developing the methods. T.C. coordinated the running of the study and conducted the interviews. T.C., D.M., J.J. and K.M. read transcripts, developed the analytical framework and contributed to the analysis. T.C. drafted the manuscript. All authors contributed to the interpretation of the analysis and critically revised the manuscript. T.C. and J.J. are guarantors.

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## Conflict of interest

B.W.M. reports consultancy for ObsEva, Merck, Merck KGaA and Guerbet. No further competing interests exist.

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